

HONORING THE DYING: COUNTING THE DEAD

“Rattle my bones over the stones, I am only a pauper that no one owns”
—anonymous

The care that we receive when dying—and the way our bodies are treated following death—are clear indicators of our value in society. Until recently, people with developmental disabilities were not considered worthy of occupying the same burial grounds as the rest of the populace. They were hastily interred and forgotten in inaccessible paupers' fields, without stones or markers to honor them. In the belief that significant improvements to quality of life can result from the study of mortality, seven NCI states have become pioneers in this field. A sampling of their efforts is reviewed in this issue of *The Indicator*.



Photo by: Patricia E. Deegan

WYOMING: SMALL—CURIOUS—COMPETITIVE

“People receiving developmental disabilities services in Wyoming enjoy a progressive system, safety, and adequate funding. It’s not that we’re geniuses ... we’re just so small.” —Jon Fortune, senior policy and research analyst, Wyoming Developmental Disabilities Division

The essence of country life is alive and well in Wyoming, a state described as “profoundly” rural. Its

population of 516,000 works out to just 5.1 persons per square mile. Former governor James Geringer called the state “a small town with really long streets.” Yet Wyoming is second to none in the attention it has paid to tracking mortality data in the developmental disabilities population. When asked why this is so, DDD program manager Jon Fortune wryly notes that fascination with all things, big and small, is a native trait. “We in Wyoming are extremely curious and competitive ... if a neighbor’s got a new

WYOMING: SMALL—CURIOUS—COMPETITIVE (continued from page 1)

tractor on the next farm, twenty miles away, we just have to know *everything* about that tractor.”

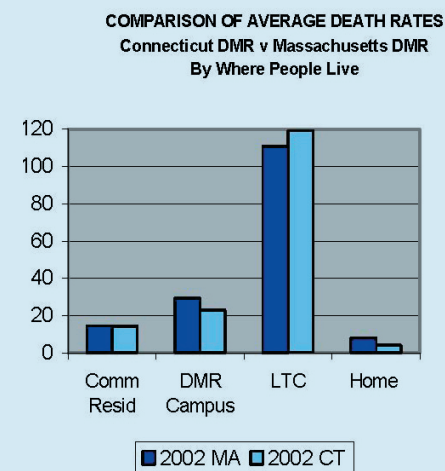
Eighteen hundred people over the age of three are on developmental disabilities services waivers in Wyoming; three thousand children receive early intervention services, and one hundred thirty consumers with acquired brain injuries receive supports. There’s barely any wait, if any, for services: Wyoming had no waiting list throughout 2005. “Having good oversight and sufficient funding, we believe our people have better health and longevity than they would without federal support,” Fortune attests. And the state has made dramatic progress since the early 1990s, when a class-action lawsuit was filed against the Wyoming State Training School. At the time, 50 percent of people enrolled expressed satisfaction with their services. Today, the figure exceeds 90 percent.

“With an average of fewer than nine deaths per year, there is little use in taking these numbers outside of Wyoming to make generalizations. There are, however, some interesting trends that were noted from the data.” —*Living Well with CMS Funding: A Study of Mortality in Wyoming* —Newman, Heinlein, Fortune, and Heath, 2005

The Wyoming DDD has been collecting mortality data for seven years. “We don’t have many people die, says Jon Fortune —fewer than nine a year—and deaths due to harm, abuse, or neglect are extremely rare.” But this hasn’t stopped the DDD from continuing to explore the subject.

Community-based Care: the Debate on Death Rates

In recent years, providers of community-based developmental disabilities services in various states have refuted the claims of a controversial California study. Its authors argued that a surge in death rates occurred when persons with developmental disabilities were discharged from institutional to community-based care (Strauss, Kastner & Shavelle, 1998; Shavelle & Strauss, 1999). Counterarguments came from Arizona, Wyoming, and the state of Washington. Researchers Ken Heinlein and Jon Fortune pointed to published research that showed “no significant differences between those who stayed at Wyoming State Training School, and those who moved, in terms of factors for mortality ... [1995]” And recent mortality data from CT and MA are consistent with these arguments. The graph below compares average death rates (expressed per 1,000 population) in CT and MA by where people live. The pattern is quite similar across the two states.



Source: State of Connecticut DMR Health and Mortality Review 2004 Annual Report

Mortality data collected includes:

- cause of death;
- residential provider;
- waiver type;
- age;
- gender;
- diagnoses; and,
- where death occurred.

Reviews and Uses of Data

Last year, the Wyoming DDD established a mortality review committee, to identify trends and ensure that appropriate supports were provided to the deceased. Its membership includes medical and certification professionals and DDD personnel.

Wyoming currently uses mortality data for two chief purposes: in federal reviews of waivers, and to educate providers.

Looking to the Future

Encouraged by an increase in rates of consumer visits to doctors for physicals and other health-related exams in each of the years that the state has gathered mortality data, state agency officials are working to

identify key related factors and trends which include:

- early identification of preventable injuries and illnesses;
- refined and improved reporting mechanisms for death and at-risk factors;
- analysis of quality-of-life factors in relation to deaths;
- analysis of rates of mortality type in relation to disease prevention;
- analysis of levels and types of service in relation to mortality trends;
- analysis of community supports for health care, specifically rural; and,
- analysis of adequacy of health-care services and professionals in small towns.

In the next decade or two, Jon Fortune foresees that Wyoming will collect and analyze mortality data that is increasingly related to issues of disease prevention and healthy living. He is convinced that adequate, sustainable supports, and the practice of individual budgeting, can help to maintain low mortality rates. Despite the scarcity of comparative data from other states, Wyoming will blaze its own trail, intent on improving the health of participants

CONNECTICUT: AN IN-DEPTH LOOK AT MORTALITY

“Over the years, Connecticut’s commissioners have felt strongly that mortality findings and recommendations will have a significant impact on the quality of our services.” —David Carlow, director of Health and Clinical Services, Connecticut Department of Mental Retardation

Connecticut has been a member of the NCI Program since 1997, when it participated as one of the original field test states. The state’s DMR has been involved in collecting mortality data for ten years. In 2002, the DMR launched an initiative to track and report on health and mortality on an annual basis. Outside consultants were hired to assess mortality rates and demographic trends. At the time, in a state profile compiled for

CONNECTICUT: AN IN-DEPTH LOOK AT MORTALITY (continued from page 3)

HSRI, NCI Program Coordinator Barbara Pankosky expressed interest in developing the area of mortality review in conjunction with other NCI states.

The consultants found that from 1996 to 2002

- mortality was highly related to client age;
- women served by the DMR were older than men, and hence had a higher mortality rate;
- the strongest predictors of mortality were

age, mobility status, amount of supervision provided, and the need for special assistance when eating; and that

- the risk of death could be expected to increase among those served by DMR, given the numbers of individuals who are elderly and therefore will become more disabled.

Trends subsequently identified, in 2004 were consistent with these findings.

Untimely Departures: Four Tiers to Mortality Review

Also in 2002, untimely deaths among individuals served by the DMR came under public scrutiny. A Legislative Program Review and Investigations Committee issued a report which was publicized by the media. As a result, Connecticut governor John Rowland issued an executive order that led to development of an organized four-tiered fatality review process. The Independent Mortality Review Board (IMRB) and a standing Fatality Review Board offer four tiers of review:

1. immediate forensic-nurse investigations;
2. regional and residential training-school investigations;
3. the Independent Mortality Review Board, chaired by DMR's director of Health and Clinical Services; and
4. a Fatality Review Board, independent of DMR, chaired by the executive director of the Connecticut Office of Protection and Advocacy (OPA).

Members of the IMRB include the DMR's directors of Health and Clinical Services, Quality Assurance, and Investigations; the state's medical examiner; representatives of the Office of Protection and Advocacy and the Department of Public Health; a private provider; a medical doctor; consumers; and a family member of an individual with developmental disabilities.

The Fatality Review Board is made up of the director of the Office of Protection and Advocacy and professionals with expertise in medicine, mental retardation, state law enforcement, and forensic investigation.

Of 102 cases reviewed by regional and training-school mortality committees in fiscal year 2004, 28 were referred to the IMRB. The board also, for quality assurance purposes, reviewed another 17 cases that had been closed by regional committees. Since its establishment, the Fatality Review Board has investigated just a handful of cases

that moved through previous tiers of review or did not fall under the jurisdiction of the DMR.

The DMR issues comprehensive annual mortality reports on trends and related information that includes quality of care, mortality and risk, and

state-to-state comparisons. The reports are easily accessible to the general public at www.dmr.state.ct.us. Click on 'Publications', and choose 'Health and Clinical Services Publications'.*

The Departed: Numbers and Profiles

On average, there are 170 to 200 deaths in Connecticut's DMR population each year. As of the fiscal year 2004 mortality report, DMR was providing services for approximately twenty thousand individuals of all ages. The FY04 death rate for all ages was 11.4 per thousand; for all over age eighteen, 13.25. The FY05 mortality report will go on line in the spring of 2006. Following a death, Connecticut collects a host of information, including:

- gender;
- age;
- level of mental retardation;
- cause of death (compared with U.S. general population);

- type of residential support;
- providers of medical and nursing care;
- location at time of death;
- quality of residential or day services, skilled nursing facilities, or medical/hospital/emergency room care;
- utilization or involvement of hospice care;
- existence of advance directives such as DNRs (do not resuscitate orders);
- requests for postmortem examinations (autopsies) and numbers performed; and
- evidence of risk factors, including mobility impairment, eating difficulties or disorders, osteoporosis, and breakdown of skin.

Toward improved clinical practice standards

"The NCI will remain one of the foundation elements in updating and improving our QA system, by integrating the many useful but fragmented components currently in place. NCI has shaped the way the department collects and analyses data, particularly abuse/neglect and incident reporting." —Barbara Pankosky, NCI

Program Coordinator, Connecticut

Repercussions of Connecticut's mortality review process have been far-reaching, including increased use of supports for hospice care, and closer oversight of

- risk factors;
- neglect or abuse;

Toward improved clinical practice standards (continued from page 5)

- do not resuscitate orders or advance directives;
- predictability and manner of deaths; and
- location and circumstances at time of death.

An extensive and growing list of quality-improvement actions has been initiated by regional committees and the Independent Mortality Review Board in fiscal year 2004. Examples include:

- referrals to the Department of Public Health for investigation of registered and licensed nurses' scope of professional practice, for investigation of Emergency Department and inpatient hospital care, and for investigation of physicians' standards of practice;
- requests to physicians for additional information and/or the rationale for treatment deci-

sions;

- systemic recommendations for monitoring of case managers, residential staff and other professionals for lack of compliance with documentation standards (e.g., incomplete or absent documentation); and
- development of health bulletins or advisories, on, for example, recognizing abdominal emergencies, hot-water safety, osteoporosis, management of dysphagia, and response to health emergencies.

According to the DMR's David Carlow, "Our work has been of great benefit toward improvement of clinical practice standards and assuring health and safety for people served by the DMR system in Connecticut."

Daring to Compare

The Connecticut DMR's annual mortality report compares data with that from neighboring Massachusetts. While larger than Connecticut, with approximately twice as many deaths annually, "Massachusetts systems and data are most similar to ours," says Carlow. And like Connecticut, Massachusetts devotes considerable time and resources to the study of mortality. The report gives readers fair warning about drawing conclusions: "There are differences in reporting requirements, age limits, and categorization of service types. Therefore, it is important to use caution when reviewing comparative information." In the FY05 mortality report, Carlow plans to compare several other states' data to Connecticut's.

Stacking Up to Connecticut

Of all states participating in the National Core Indicators Program, just seven were reporting mortality data by 2004. David Carlow muses, "It may be difficult for other states to gather, review, and analyze this type of data because they may lack suitable resources. They may not have the type of collaborative organizational structure that we have, which leads to real cohesiveness. Our Quality Assurance director sits across the hall from me, and in each regional office there's a director of Health Services who coordinates the review process. Additionally, each region has identified a nurse whose primary role is to coordinate the regional mortality review process.

"Other states may not have directors of Health Services and other health and non-health care professionals who can devote significant amounts of time to reviewing mortalities. For years our board and committee members have received robust support from the department's executive team. In Connecticut, from the time of death, there's a comprehensive reporting and analysis of how one death is different from another, and who or what factors played a significant role in the circumstances surrounding an individual's end of life."

* Related material can be found on the website in 'Publications,' under 'Quest for Excellence,' and in 'Health and Clinical Services Publications,' under 'Nursing Standards' and 'Medical Advisories.'

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Examining Deaths: Room for Improvement

NCI states collecting mortality data have encountered common stumbling blocks: inaccurate death certificates and uncooperative medical examiners. "Coroners and medical examiners often do not conduct or even release autopsies when we request them," says Shaw Seaman, incident report manager for the Washington Division of Developmental Disabilities. "We have no authority to order them to do so. This is currently beyond the scope of responsibility of our Division." In attempts to grapple with the problem,

- Arizona's DDD has expressed the need to obtain more accurate data from coroners

and medical examiners, and to have more autopsies performed, perhaps through statutory requirement.

- Wyoming's DDD is designing new reporting procedures and working to improve communication between medical examiners and division staff. Future goals include routine reviews of death certificates for complete information.
- Connecticut's DMR has begun requesting that medical examiners and local registrars of vital statistics amend incomplete or inaccurate death certificates.

VERMONT MORTALITY: BREAKING GROUND, TAKING ACTION

"Offering care to people who are terminally ill and supporting them to feel safe and cared for while they are in the dying process is an important part of developmental disability services."

—Vermont Annual Mortality Report
Vermont's Division of Disability and Aging Services (DDAS) began collecting mortality data in 1996, and shares an annual mortality report with the general public on its Web site

Vermont mortality: breaking ground, taking action (continued from page 7)

(<http://www.dail.state.vt.us>). “The point is to be publicly accountable,” says Gail Falk Director of the DDAS Office of Public Guardian.

When a person with a developmental disability dies, the Division collects information on

- age at death;
- cause of death;
- county of residence;
- type of residence;
- type of disability;
- gender;
- race; and,
- date of autopsy, if conducted.

Falk presents the data each year to a standing committee of the state’s Developmental Services Advisory Board. The committee, she says, uses her presentations to educate themselves on issues of mortality among people with developmental disabilities.

The Division uses the annual mortality report in an effort to detect areas of need. For example, concerns were raised when the number of cancer deaths associated with smoking seemed higher than that of the general population. In the following year, the numbers dropped significantly. Division managers concluded that the previous year’s data were not statistically meaningful, and their collection of information on smoking ceased.

The Numbers

Gail Falk cautions that Vermont’s figures tell a limited story, since the state is small and the number of people who die each year is low. Between fiscal year 1999 and fiscal year 2005, the low was 26, the high 40. According to the an-

nual report, the small figures make it “difficult to detect trends, and to be confident in their statistical significance even when detected.”

At the same time, Vermont has been able to make compelling observations, such as the following analysis, in a draft of the 2005 Annual Mortality Report, of deaths in nursing homes:

“In 2002, about 25% of all Vermont deaths occurred in a nursing home (most of the others were in hospitals, or at home). In contrast, only 2 of 37 deaths of Vermonters who received developmental disability services occurred in nursing homes. The rate of placement in a nursing home for a final illness (5%) was dramatically lower for people with DD than for the Vermont population as a whole and much improved over FY 2003, when 30% of DDS deaths occurred in nursing homes. In FY 2004, the Developmental Disability Services system excelled in its ability to serve people through final illness in non-institutional settings.”

From Data to Direct Action

Perhaps the most significant action Vermont’s Division of Disability and Aging Services has taken based on mortality data, according to Gail Falk, was a response to a handful of possibly preventable deaths that occurred in respite care settings. (Only one case clearly involved neglect: a person in a respite home was meant to be restricted to the first floor and died after falling down stairs). Recognizing the need for more scrutiny, the Division held a statewide meeting attended by stakeholders and facilitated by HSRI, and followed up with a systemwide distribution of information and higher expectations for responsibility in respite care homes.

Developmental Disability is Not a Cause of Death

Following a cluster of deaths at a busy, underserved rural hospital several years ago, DDAS called a meeting with hospital staff, public guardians, and the nonprofit agency for developmental disabilities services in that county. Medical professionals, Gail Falk says, have a widespread misperception that developmental disability can be a cause of death. Doctors may view people who cannot talk or walk as no different from frail elderly patients, and it is not yet common for medical practitioners to consider what quality of life means to a person with developmental limitations.

At the meeting, Division staff addressed the importance of collaboration between medical professionals, providers, and family members, since the patient may need help communicating and providers do not always have adequate medical knowledge. “We explained the role of guardians,” says Falk. “The doctors and nurses did listen; this was the important thing. It did improve communication with staff in that particular hospital.” Subsequently,

the Division prepared a two-page sheet, “When a Person with Developmental Disabilities is Hospitalized—Guidelines for Hospital Staff,” which has been distributed to each major hospital in Vermont.

Small Is Beautiful ... Pooling Resources Is Better

For those working in a small state like Vermont, the more states that collect data, the merrier. A project (funded by a Real Choices Systems Change grant and headed by Dr. Steven Staugaitis) to involve all New England states in collecting uniform mortality data is underway at the University of Massachusetts Medical School/Shriver Center for Developmental Disabilities Evaluation and Research. This inspires Gail Falk, who says, **“I’m looking forward to the time when we can combine our numbers with those from the other New England states, so that we can have large enough numbers to detect trends.”**

Aspiration: Facing a Deadly Foe

Individuals with developmental disabilities die from complications of aspiration, pneumonia, and choking at a higher rate than people in the general population. This fact is supported by mortality data from NCI states. Contributing factors include the need for assistance in eating, poor muscle function, and seizures. Initiatives to combat the problem include:

ARIZONA

1. Yearlong training in supervised residences on increased monitoring of and precautions against choking, with experts in eating disorders Karen Green McGowan of Florida and Marsha Dunn Klein of Arizona.

2. An article in DDD’s Clinical Quality Bulletin explaining risk factors and encouraging consumers with symptoms, espe-

cially with a history of aspiration, to seek prompt medical attention. Providers are urged to pay close attention to ordering chest X-rays and blood work, and to offer flu shots.

WASHINGTON

Alerts about flu, aspiration and pneumonia, and medications sent to providers, posted on Web site <http://www1.dshs.wa.gov/ddd/publications.shtml>

ARIZONA: IMPROVED MORTALITY OUTCOMES THROUGH MANAGED CARE?

“We’re like a managed care HMO, to all intents and purposes. Although we have the same service delivery problems as other states, our death rates are surprisingly low. If confirmed, the data will make a case for integrated systems of acute and long-term care.”

—Ric Zaharia, director of Arizona’s Division for Developmental Disabilities

Arizona has posed a provocative question, spawned by a singular service delivery system and a burgeoning population. Since 1988, Arizona’s developmental disabilities system has run on a unique research and demonstration Medicaid waiver program known as the Arizona Long Term Care System (ALTCS). Approved under section 1115 of the Social Security Act, DDD administers all services, acute and long-term care, provided to eligible individuals through contracts with qualified community services providers. DDD director Ric Zaharia says the program allows for optimal coordination among providers of hospital, convalescent, and residential care.

Arizona is also one of the largest of NCI states to collect mortality data. In the autumn of 2003, the state had 22,208 people enrolled in its developmental services system. Between October 1, 2003 and September 30, 2004, 216 of these people died. For the past two years, Arizona’s DDD has offered its mortality data on its Web site, <http://www.de.state.az.us/ddd/>.

Modest Death Rates: Checking the Numbers

Between 2002 and 2004, Arizona DDD statistics revealed a death rate ranging from 7.7 to 9.5 per 1000. There’s a working hypothesis afloat in the DDD that these figures are significantly

lower than in other states, and that the difference may reflect the overall high quality of integrated ALTCS services. The Division awaits confirmation of its mortality data in an analysis by the University of Arizona, expected in the summer of 2006. The study will also include a review of data from Connecticut and California. According to Ric Zaharia, “We want to make sure that our numbers are correct, and we want a benchmark against states with comparable data. Are we correct that ours is a healthy population where mortality is concerned?”

Mortality data collected by Arizona’s Division of Developmental Disabilities includes:

- deaths per month;
- deaths per year;
- deaths per district;
- deaths per 1000 per district;
- cause of death;
- residence at time of death; and,
- location of death.

Data are analyzed separately for the Arizona Training Program, the state’s sole large congregate residence, which houses 145 individuals. All data are reported in the overall mortality rate.

“The mortality review process seeks to answer the following questions: Could the death have been prevented? Are there service system issues that need to be addressed? What actions should the Division take to improve the health and safety of the people it serves?” — Arizona DDD Mortality Report 2004

Until 2002, deaths were reviewed solely by the DDD’s medical director. In October of that year, the division formed a mortality review

committee, whose members include representatives of DDD urban and rural district offices, the state Department of Economic Security, staff from ALTCS compliance and risk management units, provider agency staff, and families.

The committee makes recommendations to DDD’s management team regarding training and education, development of policies and procedures, improvements to facilities or equipment, corrective-action plans for providers, and referrals to licensing bodies for investigation. An area that could use improvement is the accurate reporting of causes of death by medical examiners and coroners. “We would like to obtain more accurate data,” says Ric Zaharia, “and get more autopsies done, perhaps through a statutory requirement.”

Why Track Mortality if It Isn’t a Problem?

Arizona’s DDD has responded to mortality data with preventive health initiatives and tightened expectations for vendors regarding monitoring, oversight, and contract compliance. “Other than tracking down suspicious deaths,” says Zaharia, “our mortality review hasn’t spawned many initiatives, because this looks like a normal population. Once the University of Arizona tests our data, we’ll know where to go next. Do we want to continue to devote resources that could be used elsewhere to review mortality, if it is not a problem?”

